

Learning Disabilities: Young people aged 14+ and adults

Executive summary

People with learning disabilities have poorer health than their non-disabled peers. They have higher levels of mental illness, chronic health problems, epilepsy, and sensory problems. Life expectancy of people with learning disabilities in North Somerset is 64 years, much lower than the North Somerset average of all residents of 79.9 for men and 83.9 for women.

Nationally the number of adults with learning disabilities is increasing and is predicted to increase by 1% each year for the next 15 years. GP practice data recorded 809 adults with learning disabilities in North Somerset in 2011-12. The GP practice prevalence of learning disabilities (0.48%) was higher than the average for England (0.45%) and has increased over the last few years.

In the same period 512 adults aged over 18 with a learning disability were accessing local authority social care services in North Somerset. The rate of adults in local authority services with a learning disability was lower in North Somerset (3.42 per 1000) than England (4.27 per 1000). North Somerset has one of the biggest differences in GP practice and local authority recorded prevalence of learning disabilities nationally. The prevalence of children reported as having learning disabilities in North Somerset (12.3 per 1000) is much lower than the national rate (24.6 per 1000) and has declined over time.

People with learning disabilities are more likely to be exposed to the social determinants of poor health such as poverty, poor housing conditions, unemployment, discrimination and social isolation.

Although the proportion of people with learning disabilities known to social services who are employed (9.3%) is higher than the national average (6.3%), rates are still low and most people are working less than 16 hours a week and on a voluntary basis. In 2010-11, North Somerset has a similar proportion of people with learning disabilities in settled accommodation (55%) than the England average (59%). Studies have indicated that people with learning disabilities have high levels of untreated dental decay. Levels of obesity and underweight are also high, reflecting low levels of physical activity and unhealthy diets - less than 1 in 10 adults has a balanced diet. There were 75 referrals under the safeguarding procedures in 2010-11.

Current services

GP Practices: In 2011-12, 468 health checks were undertaken in GP practices for people with learning disabilities in North Somerset. Uptake in North Somerset (72%) was higher than the national average (53%) and has risen from 0% in 2008/09. The quality and outcomes of the health checks are unknown.

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Hospitals: The level of recording of learning disabilities in hospitals (39%) is low but higher than the national average (27%) and has been rising. Recording of learning disabilities in psychiatric in-patient has historically been very low. People with learning disabilities are more likely to be admitted as an emergency compared with the general population, and over the years the proportion admitted as an emergency has risen. Provision of learning disabilities liaison nurses in hospitals accessed by North Somerset residents is variable.

Health promotion: National data indicates that uptake of cancer screening in people with learning disability is low. There is no local mechanism to monitor uptake of cancer screening or other programmes (e.g. Abdominal Aortic Aneurysm (AAA) screening, diabetic retinopathy). A new scheme to encourage uptake of sports in people with learning disabilities ‘Sportarray’ started in 2013 funded for 3 years.

Community Team for People with Learning Disabilities (CTPLD) is a joint, multidisciplinary, co-located team offering health and social care services to people with a learning disability. During 2011-12, social services saw 421 adults. The number of people transitioning from children to adults services is expected to rise from 39 in 2012-13 to 59 in 2016-17.

Other support: In 2011, the estimated number of people with learning disabilities aged under 65 years and living with a parent was 242. The Shared Lives Scheme provides support and accommodation in a family home for people with learning disabilities. Support for advocacy is provided through a number of organisations. In 2012, 210 adults received personal budgets. Specialist educational provision is offered at Weston College.

Community views: Consultations with people with learning disabilities and their carers have identified priorities as increasing employment; reducing levels of discrimination (bullying / hate crime); increasing opportunities for friendships and relationships; increasing community and one to one support; addressing underweight and obesity; and improving care in Weston Hospital.

Challenges for consideration

A number of challenges are listed at the end of this report and these take into account recommendations from the Winterbourne View review. These include developing a joint register of people with learning disabilities; moving people out of residential care into supported living; reducing out of area placements; increasing and monitoring the quality of service providers; improving mental health provision; and increasing employment opportunities.

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1 Why is this area important?

*Valuing People*¹, the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition of learning disabilities.

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which are present from childhood with a lasting effect on development

Historically, local services in North Somerset have adopted a working definition that adults with learning disability are those who have an assessed IQ of less than 70.

A person's IQ has often determined what services they will receive and from what source. In many cases, this leads to services being provided on the basis of what is available from within learning disability services, rather than being based on a package of support drawn from a number of sources and agencies. In considering these definitions, care needs to be taken to ensure that planning of services and access to them is sufficiently flexible to help those who have borderline needs.

People with learning disabilities have poorer health than the general population, differences in health status that are, to an extent, avoidable². They are also less likely to access healthcare.

People with learning disabilities have a shorter life expectancy and increased risk of early death compared to the general population. Whilst life expectancy is increasing for people with mild learning disabilities and approaching that of the general population, the mortality rates among people with moderate to severe learning disabilities are three times as high as in the general population³.

Mental illness, chronic health problems, epilepsy, and physical and sensory problems are more common amongst people with learning disabilities, yet they are less likely to receive regular primary care health checks and access routine screening than the general population.⁴ Given the evidence of their greater health needs, it would be expected that people with learning disabilities would be accessing primary care services more frequently. However, primary care access rates for people with learning disabilities are in fact lower than might be expected⁵.

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People with learning disabilities have complex health needs, some of which they share with the general population and some of which are different. The interactions of physical, behavioural and mental health issues can appear to be difficult to interpret and may cause illness to be overlooked so that serious conditions can present too late for prevention or cure. This *diagnostic overshadowing* may lead to some health care professionals not investigating early enough as they rationalise new symptoms as being part of the learning disability rather than explaining new symptoms. This is particularly the case with mental health issues⁶.

People with learning disabilities experience many differences in their life experiences than the general population. They do not have the same control over their own lives as the rest of society and face challenges and prejudice every day. Mencap⁷ research suggests:

- Less than 1 in 5 people with a learning disability work (compared with 1 in 2 disabled people generally), but we know that at least 65% of people with a learning disability want to work. Of those people with a learning disability that do work, most only work part time and are low paid.
- Just 1 in 3 people with a learning disability take part in some form of education or training.
- Children with a learning disability are often socially excluded and 8 out of 10 children with a learning disability are bullied.
- 1 in 2 families with a disabled child live in poverty.
- At least half of all adults with a learning disability live in the family home - meaning that many don't get the same chances as other people to gain independence, learn key skills and make choices about their own lives.

*Valuing People*¹ (2001) was the first White Paper on learning disability for thirty years and set out an ambitious and challenging programme of action for improving services.

The paper is based on the fundamental message that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens. With the right support, most people with a learning disability in the UK can lead independent lives.

In June 2011, Winterbourne View Hospital, a private hospital located South Gloucestershire offering a specialist resource for adults with challenging behaviour and learning disability was closed following the uncovering of catalogue of shocking events and large scale abuse. The subsequent reviews have resulted in a series of clear recommendations for changes to services for people with learning disabilities at a national level. Key points to consider include the following:

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- Improve quality of care, care planning, and the inclusion of meaningful activities to do in the day
- All parts of the system have a duty to drive-up standards
- There should be zero tolerance of abuse
- Reduce the number of people placed in in-patient services for Assessment and Treatment (A&T)
- Improve access to support and services locally, near to family and friends
- Agree contracts that meet both the needs of the patients and the needs for ongoing monitoring.
- Ensure robust monitoring systems are in place

In North Somerset work is coordinated through the Learning Disability Partnership Board which has representation from the council, health, the voluntary sector, carers and users of services. Further information about the Partnership Board can be found on the following website <http://www.ld4u.org.uk/default.aspx?page=26255>

This Learning Disabilities chapter of the JSNA provides a rapid review of the needs of the learning disability population in North Somerset. Due to time constraints there are some areas where information or analysis is currently missing. These include the following:

- Comparison of prevalence of learning disabilities in schoolchildren with the numbers receiving Free School Meals.
- Detailed review of hospital admissions data , both elective and emergency;
- Numbers assessed by the CTPLD and details of the services received;
- Stakeholder views, including social workers and GPs, including issues related to transition and the primary / secondary care interface.

2 What are the needs of the population?

There is no definitive source of precise information on the number of people with learning disabilities nationally or in North Somerset⁸. However there are a number of sources of data on people with learning disabilities that provide an indication of likely need. These sources are services use data, population surveys and administrative databases.

2.1 General Practice (GP) data

General practices keep registers of people with learning disabilities as part of the Quality and Outcomes Framework (QOF). In 2011-12, there were 809 adults aged over 18 registered with a GP in North Somerset with learning disabilities.

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Based on this data, the prevalence of learning disabilities in adults in North Somerset is 0.48%, higher than the England average of 0.45%.

General practices are increasingly recognising learning disabilities. In 2006-07, North Somerset had a similar prevalence of GP diagnosed learning disabilities to the England average. However between 2006-07 and 2010-11 the number of people with learning disabilities diagnosed in North Somerset general practices increased by 47% compared to 42% in England. This has resulted in a comparatively higher prevalence of learning disabilities in North Somerset general practices.

There was a substantial rise in the diagnosed prevalence of learning disabilities between 2007-08 and 2008-09 in North Somerset (19%). Large increases were also seen in England during this period (11%). This coincides with the introduction of annual health checks for adults with learning disabilities as part of a Directed Enhanced Service (DES) in 2009⁹. In the most recent years (2010-11 and 2011-12) the increases have been considerably lower (Table 1).

Table 1: Trends in the prevalence of Adults aged over 18 with Learning Disabilities registered with General Practices (2006-07 to 2011-12)

	2006/07	2007/08	2008/09	2009/10	2010/11	2011-12
North Somerset						
Number	549	614	732	782	816	809
% adult population with LD	0.27%	0.30%	0.44%	0.47%	0.48%	0.48%
% increase from previous year	-	11.8%	19.2%	6.8%	4.3%	-0.9%
England						
Number	139,321	144,909	160,165	179,064	188,819	198,877
% adult population	0.26%	0.27%	0.4%*	0.42%	0.43%	0.45%
% increase from previous year	-	4.0%	10.5%	11.8%	5.4%	5.3%

In 2008-09, only 1 decimal point was report on national prevalence QOF data tables.

Source: Quality and Outcomes Framework, NHS Information Centre

There are significant variations in the prevalence of learning disabilities between practices in North Somerset, ranging from 0% in St Georges Surgery to 1.3% in Graham Road Surgery (Figure 1). There is a higher prevalence of learning disabilities in general practices in more deprived areas. Nationally it has been

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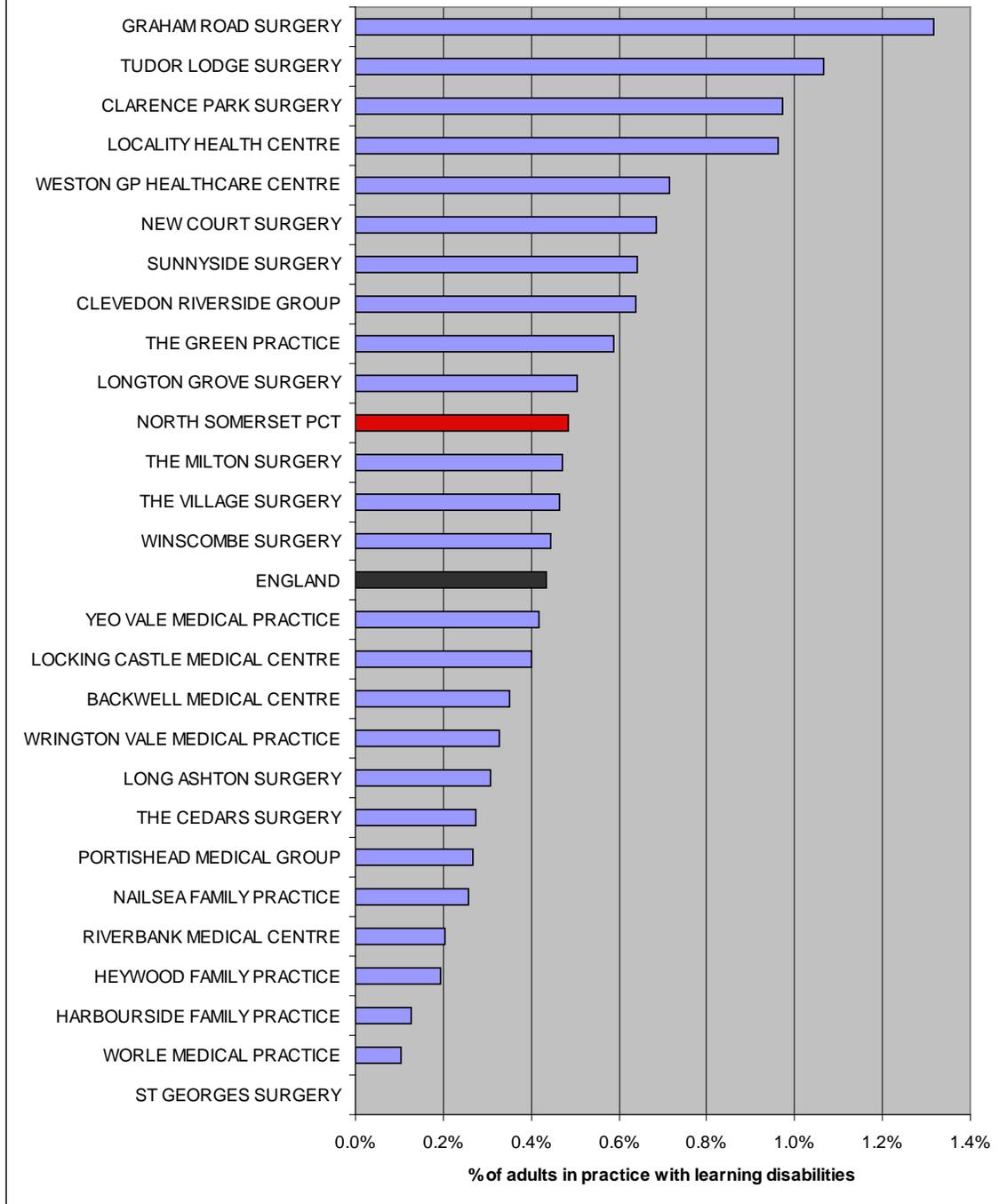
shown that people with learning disabilities are more likely to live in areas characterised by high levels of social deprivation¹⁰. This is the case both for people living in private households and supported accommodation.

Although QOF data provides a useful indication of local need there are several limitations with this data. Firstly, there is no standard definition for learning disabilities used in the QOF registers. The QOF registers give no indication of severity or any demographic details such as age, sex or ethnicity. Therefore it not clear if the higher QOF prevalence of learning disabilities in North Somerset compared to England reflects true prevalence. Research has demonstrated that general practices often find it difficult to accurately identify those with learning disabilities¹¹.

Figure 1: QOF prevalence of learning disabilities in adults (age 18 and over) in North Somerset General Practices

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**QOF Prevalence of learning disabilities in adults (age 18 and over)
in North Somerset General Practices**



Source: Quality and Outcomes Framework, NHS Information Centre

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2.2 Local Authority Data

North Somerset Council keeps a database of those people with learning disabilities who access social care services. In 2011-12, 512 adults aged over 18 with a learning disability were known to the local authority and receiving support from social care (Table 2). This figure is much lower than the total listed with in GP practice QOF data. North Somerset has one of the biggest gaps between GP recorded learning disabilities and local authority data.¹²

Table 2: Adults with learning disability known to North Somerset social care (2011-12)

	Age 18 to 64	Age 65 +	Total
Female	175	27	202
Male	246	64	310
Total	421	91	512

Source: SWIFT data – North Somerset Council, May 2012

In 2010-11, the proportion of adults known to local authorities with a learning disability was substantially lower in North Somerset (3.42%) compared to the national average (4.27%). Over the last four years, the numbers in North Somerset have been steadily falling until 2011-12 when they rose by 19%. The proportion of adults with learning disability known to local authorities across England increased during the period 2008-2011 (Table 3).

Table 3: Trends in adults (18 to 64) with learning disability known to Local Authorities (2008/09 – 2010/11)

Period	Number of adults	Rate per 1000		
		North Somerset	South West	England Average
2011-12	512	NA	NA	NA
2010-11	430	3.42	4.48	4.27
2009-10	445	3.58	4.61	4.21
2008-09	585	4.73	4.49	4.14

Source: Learning disabilities profile, North Somerset 2012
<http://www.improvinghealthandlives.org.uk/profiles/index.php?pdf=E06000024> and North Somerset Council SWIFT data for 2011-12.

The majority (97%) of people with learning disabilities accessing social care

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services in North Somerset are white British in origin. Other ethnic groups are represented, but in very low numbers or single individuals (SWIFT data – North Somerset, May 2012).

2.3 Population surveys

The data systems Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) can be used to provide estimates of current prevalence and projections of potential numbers of people with learning disability in North Somerset.

These models estimate that approximately 20 in 1000 people in the UK have mild to moderate learning disabilities, and 3-4 in 1000 have severe or profound learning disabilities.¹³ The Department of Health has produced estimates of adults with learning disabilities based on research studies in several parts of England. Applying this data to the local population provides an estimate of the number of people with learning disabilities living in North Somerset.

In 2011 there were estimated to be 4,011 people with learning disabilities living in North Somerset, 817 (20.4%) of whom have moderate or severe learning disabilities (Table 4). Those with moderate to severe learning disabilities are most likely to need access to specialist services.

The estimated number of moderate or severe people with learning disabilities is very similar to the number identified through QOF in 2010-11 (n=809) and higher than the number known to the local authority (n=512) (see previous section).

Table 4: Estimated number of adults aged over 18 with learning disabilities in North Somerset 2011

Age 18-64	Age 18-64	Age 65+	Total
Baseline learning disability	3,088	923	4011
Moderate/severe learning disability	693	124	817
Severe learning disability	182	NA	-
Challenging behaviour	58	NA	-
Autistic spectrum	1,285	NA	-
Moderate/severe LD living with parent	242	NA	-
Downs Syndrome	80	2	82
Downs Syndrome with dementia	8	0	8

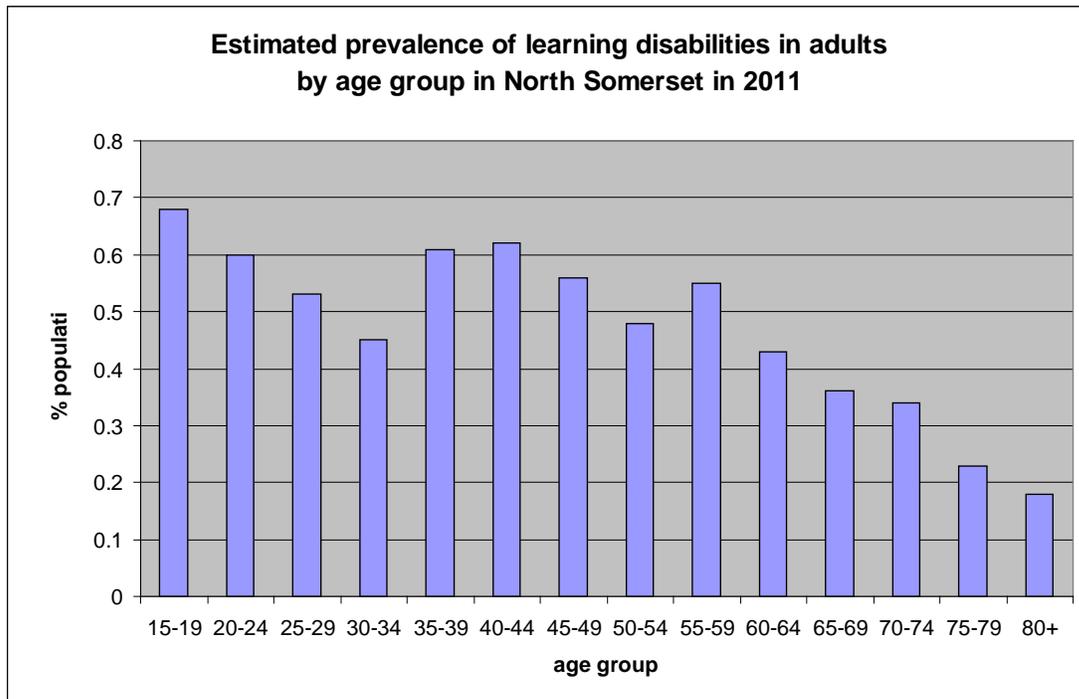
Source: Department of Health. PANSI and POPPI accessed 5.5.12

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Prevalence of learning disabilities is highest in the younger age groups (age under 20s) and declines with age with the exception of a second peak in those aged 35-44. This is shown in Figure 2.

There are estimated to be 82 people with Downs Syndrome living in North Somerset. Downs Syndrome increases the risk of early dementia. Of the 82, it is estimated that 8 will have dementia.

Figure 2: Estimate prevalence of learning disabilities in adults by age group in North Somerset 2011



Source: Department of Health. PANSI and POPPI accessed 5.5.12

2.4 Children with learning disabilities

Information on the number of children with learning disabilities provides data on the current needs of children and gives an indication of future needs for adult services. For children, information is recorded on the numbers of children with special educational needs. Learning disabilities is included in the categories for special education need and is split into four categories:

- Specific Learning Difficulty (like dyslexia);

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- Moderate Learning Difficulty;
- Severe Learning Difficulty; and
- Profound and Multiple Learning Difficulty.

The level of educational input received by children is then split into three categories:

- **School Action:** evidence of additional need which is met by the school providing additional resource of different teaching techniques.
- **School Action Plus:** evidence of additional need which is met by the school providing additional resource of different teaching techniques and interventions provided by outside agencies.
- **Statement of Special Educational Need:** where there is evidence that a child is not making progress under school action or school action plus or they require a lot of additional help.

This data is collected by the Department for Education in the national school census. There are two main limitations with this data¹⁴. Firstly the nationally reported data only includes those who have a Statement or who are School Action Plus so are in part a reflection of the differences in local arrangements for providing children with statements. Secondly the data at a national level only reports on primary need although information on secondary needs is available locally and has been included in this report.

The total number of children with learning disabilities in schools reported in the School census has been declined between 2008 and 2011 (table 5). The rate of children with learning disabilities in North Somerset schools has also reduced over these three years (table 6). This contrasts with the national picture where rates have been steadily increasing. Most children with a learning disability had a moderate learning disability.

Table 5: Number of children with learning disabilities in schools in England, South West and North Somerset (2008 – 2011)

	Autistic Spectrum	Moderate LD	Severe LD	Profound / Multiple	Children with LD
Jan 2008	149	294	104	26	424
Jan 2009	151	280	111	19	410
Jan 2010	158	268	103	19	390
Jan 2011	156	245	93	24	362

Source: North Somerset Learning Disabilities Profile (2012); school census

Table 6: Rates of children per 1000 with learning disabilities in schools in England, South West and North Somerset (2008 – 2011)

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	Autistic Spectrum		Moderate LD		Severe LD		Profound / Multiple		Children with LD	
	NS	Eng	NS	Eng	NS	Eng	NS	Eng	NS	Eng
Jan 2008	5.1	5.9	8.3	21.2	3.6	3.6	0.9	1.1	14.5	26.0
Jan 2009	5.2	6.3	9.1	21.3	3.8	3.6	0.7	1.2	14.0	26.0
Jan 2010	5.4	7.0	9.6	20.9	3.5	3.6	0.7	1.2	13.3	25.5
Jan 2011	5.3	7.6	10	19.8	3.2	3.6	0.8	1.2	12.3	24.6

Source: North Somerset Learning Disabilities Profile (2012); school census. NS = North Somerset, Eng = England

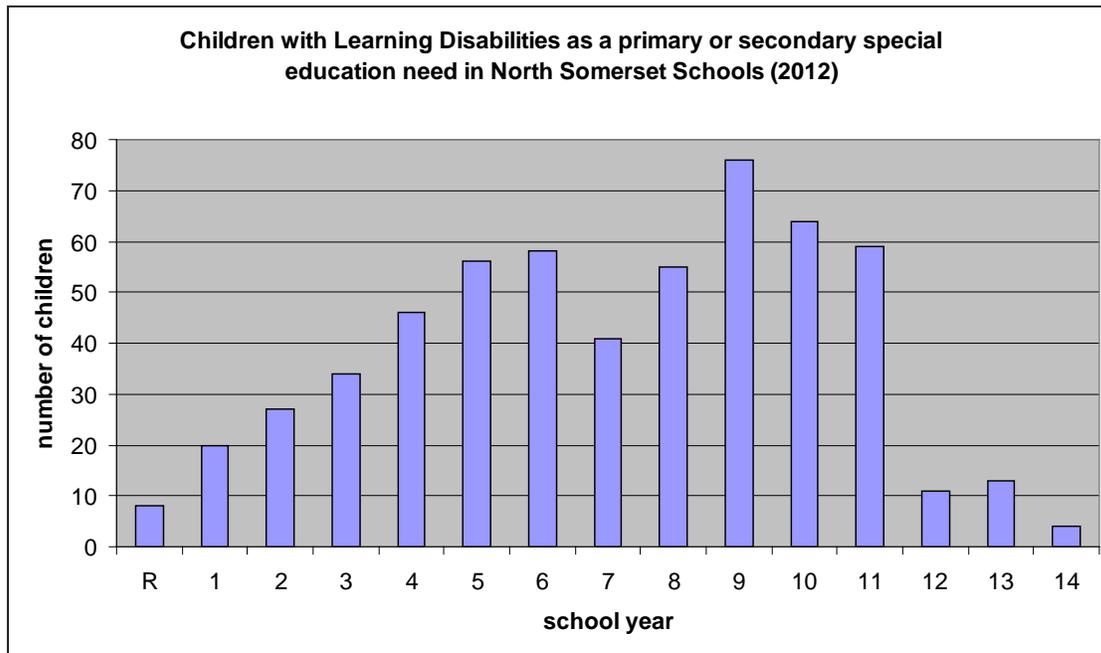
Local data indicates that 112 pupils had a secondary special education need of learning disabilities in 2012. Of these children the three most common primary special educational needs were behaviour, emotional & social difficulties (41%); speech language and communication needs (20.5%); and autistic spectrum disorder (15%).

Of the 461 pupils recorded locally with a primary special educational need of learning disabilities in 2012, 45% also had a secondary need recorded. In this group the most common secondary needs were speech language and communication needs (14%), behaviour, emotional & social difficulties (12%); physical disability (7%) and autistic spectrum disorder (5%).

More males than females are affected, with 1.8 boys for every 1 girl. The number of pupils with learning disability increases with age peaking at year 9 (age 13-14).

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Figure 3: Age profile of children with Learning Disabilities as a primary or secondary special education need in North Somerset Schools (2012)



Source: School census, children with statements or School Action Plus.

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2.5 Future Projections

Nationally there is evidence that the number of adults with learning disabilities is increasing. Evidence suggests that the number of people with severe learning disabilities will increase by around 1% each year for the next 15 years due to three main factors^{15,16}.

- An increase in the proportion of young adults from South Asian communities where prevalence of learning disabilities is higher
- An increase in the number of young people with severe and complex needs surviving until adulthood
- A sharp rise in the reported numbers of school-aged children with autistic spectrum disorder, some of whom will have learning disabilities
- An increase in life expectancy, especially among people with Downs Syndrome.

In addition, North Somerset is projected to have a large rise in its population, exceed national growth and happening more rapidly than the national average

By 2030 North Somerset is projected to have a 30% increase in the numbers of people with moderate to severer learning disabilities. The highest rate of increase is expected in the older age groups however the absolute numbers of older people with learning disabilities remains small. The projected age profile of people with learning disabilities will need to be taken into account in the planning of future services, including the design of day care and the type of living accommodation offered (Table 7).

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Table 7: Projected numbers of adults with moderate to severe learning disabilities in North Somerset (2011 – 2030)

	2011	2015	2020	2025	2030	%increase 2011 -20	%increase 2011 - 30
Age 18-24	93	93	91	95	106	-2.2	14.0
Age 25-34	116	139	155	161	163	33.6	40.5
Age 35-44	181	177	193	225	241	6.6	33.1
Age 45-54	162	176	176	170	187	8.6	15.4
Age 55-64	141	138	157	173	171	11.3	21.3
Age 65-74	82	96	101	100	113	23.2	37.8
Age 75-84	30	34	41	51	53	36.7	76.7
Age 85 +	12	14	17	21	27	41.7	125.0
Total	817	867	931	996	1061	14.0	29.9

Source: Department of Health. PANSI and POPPI accessed 5.5.12

The overall proportion of people living with learning disabilities at all levels, mild, moderate and severe, is predicted to rise between 2011 and 2030. The number of 4,011 in 2011 is expected to rise to 5,231 by 2030, a rise of 30.4%¹⁷.

A group that is expected to rise in number considerably over this period is the group of people with learning disabilities living with their parents. This is predicted to rise by 79% in North Somerset from 242 to 305 over the 19 year period¹⁵.

Down's syndrome is the most common inherited cause of learning disability. Prevalence rates would suggest a figure of 82 people aged 15 to 64 living in North Somerset with Down's syndrome. People with Down's syndrome are at an increased risk of Alzheimer's disease and many develop dementia as they reach older age. Projections show an anticipated rise of people living with Down's syndrome and dementia by 25% between 2011 and 2030 (Table 8). These figures should be interpreted with caution as it is difficult to accurately predict population changes over a period of several decades.

Table 8: Projected numbers of people with Down's syndrome in North Somerset (2011 – 2030)

	2011	2030	% increase 2011-2030
Down's syndrome	82	99	20.7%
Down's syndrome and dementia	8	10	25%

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2.7 Health and wellbeing outcomes

People with learning disabilities, especially people with less severe learning disabilities, are more likely to be exposed to the social determinants of poor health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination¹⁸.

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities¹⁹ and a number of syndromes associated with learning disabilities are also associated with some specific health risks²⁰. These include:

- congenital heart disease which is more prevalent among people with Down's syndrome and Williams syndrome;
- early onset dementia which is more common in people with Down's syndrome;
- hypothalamic disorders which are more prevalent among people with Prader-Willi syndrome;
- mental health problems and challenging behaviours which are more prevalent among people with many learning disabilities;
- obesity which is more prevalent among people with Prader-Willi syndrome, Cohen syndrome and Bardet-Biedl syndrome.

The median age of death of people with learning disabilities in North Somerset is 64 years, higher than the national average of 55 years.²¹ This compares to an average life expectancy of 79.9 years for men and 83.9 years for women (2008-2010). This data should be viewed with caution as learning disabilities not consistently recorded on death certifications, where this data originates.

People with learning disabilities may have poor bodily awareness and limited communication skills may further reduce their ability to convey identified health needs effectively to others. As a result, the carers' role is vital in the identification and communication of health needs for many people with more severe learning disabilities.

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2.8 Dental health

Studies have shown dental health is known to be poor in people with learning disabilities, with high levels of untreated dental decay and gum disease.²² There is no local data on oral health in people with learning disabilities.

2.9 Lifestyle

It has been shown that less than 1 in 10 of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables²³. Many carers also have a generally low level of knowledge about public health recommendations on dietary intake.

In addition, the majority (over 80%) of adults with learning disabilities are not particularly active, with levels of physical activity falling below the Department of Health's minimum recommended level, representing a much lower level of physical activity than the general population (53%-64%)¹⁹. People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity.

People with learning disabilities are much more likely to be either underweight or more obese than the general population. Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity¹⁹. These high levels are likely to be associated with an increased risk of diabetes within this population group.

There are fewer adults with learning disabilities who smoke tobacco or drink alcohol compared to the general population. However, rates of smoking among adolescents with mild learning disability are higher than among their non learning disabled peers¹⁹.

There is evidence to suggest that people with learning disabilities face particular barriers in accessing sexual health services, and the informal channels through which young people learn about sex and sexuality²⁴.

A range of organisational barriers have been identified that affect people with learning disabilities when accessing healthcare services¹⁶. These include:

- scarcity of services;
- physical barriers to access;
- failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning

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disabilities;

- variability in the availability of interpreters for people from minority ethnic communities;
- 'diagnostic overshadowing' (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities);
- disablist attitudes among healthcare staff.

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3 Current service provision

There are a range of services available for people with learning disabilities in North Somerset. This section provides detail on some of these. For further information, additional detail can be found on www.LD4U.org.uk

3.1 Health and Social Care

3.1.1 Primary Care

Research has shown that people with learning disabilities visit their GPs as often as the general population. However given the higher health needs in people with learning disabilities, the frequency of visits should be higher. Comparison of consultation rates with GPs to those of patients with other chronic conditions suggests that primary care access rates for people with learning disabilities are lower than might be expected. Those that do visit their GP more frequently tend to be female, older in age and have a paid carer.

In 2009 a national scheme aimed at providing health checks to people with learning disabilities was launched. The introduction of this scheme has been shown to be effective in:

- Detecting unmet, unrecognised and potentially treatable health needs, including conditions such as cancer, heart disease and dementia
- Targeting actions to address these health needs ²⁵

As a result of this scheme there were 468 health checks undertaken in people with learning disabilities in North Somerset in 2011-12. This represents 72% of the 650 adults with learning disabilities known to both GPs and social services. This means that **28% of adults with learning disabilities did not receive a health check**. However, North Somerset and the South West have higher uptake rates than the average for England as a whole (see Table 9 below). The content and outcomes of these checks are unknown.

It should be noted that the denominator used in the national definition of uptake is based on the numbers of people known to both GPs and social care. This number is lower than those on the QOF register and estimates of those with moderate to severe learning disabilities. Therefore uptake rates would be considerably lower if these populations were those used as the denominators.

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Table 9: Trends in the proportion of adults with learning disabilities known to both general practice and social services who had a health check (2008-9 – 2010-11)

	2008-9	2009-10	2010-11	2011-12
North Somerset	0%	46%	61%	72%
South West	30%	57%	65%	69%
England	23%	41%	49%	53%

Source: Learning Disabilities Observatory

3.1.2 Secondary care

Across England, both the NHS total expenditure and the expenditure per person on services for people with learning disabilities varies considerably. In addition there is also great variation in the specific services provided to people with learning disabilities by specialist NHS Trusts. Overall, people with learning disabilities tend to have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialties when compared to the general population²⁶.

Hospitals can only make appropriate and reasonable adjustments for people with learning disability if they know that they need to. The identification of learning disability is incredibly important when a person is admitted to hospital as adjustments will always be required to make sure that these patients understand fully what is happening and what they are consenting to, and that doctors and nurses take their learning disability into account in assessing symptoms and progress. Recording this statistically is also important to the hospital first so it can check reasonable adjustments are being made and second because in many cases hospitals get paid more for treating people who have a learning disability, as more care is needed. However, learning disability does not appear to be routinely or consistently recorded on admission to hospital.

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Table 10: Total number and proportion of episodes of general hospital care where the individual's learning disability is recorded

Period	Total number of episodes where learning disability identified	Total number of episodes where learning disability not identified	North Somerset (%)	South West (%)	England Average (%)
2005-06	139	435	24.22	23.51	22.50
2006-07	126	452	21.80	28.03	23.63
2007-08	172	353	32.76	24.75	24.58
2008-09	231	364	38.82	27.17	27.12

Learning Disabilities profile: www.ihal.org.uk/profiles

Table 10 presents the number and proportion of hospital admissions for general care in which the individual's learning disability is specifically recorded. Recording levels of 39% in 2008-09 are significantly higher in North Somerset than the average for England (27%). These figures show that despite an increase in the proportion of recording status over the last four years, over half (61%) of those with a learning disability entering hospital locally still do not have their status recorded.

People with learning disabilities are also more likely to be admitted to hospital as an emergency. Nationally 50% of admissions for people with a learning disability are emergency admissions compared with 31.1% in those without.²⁷ Within North Somerset, the proportion of admissions that were emergencies has risen but was lower than the England average for 2008-09 (table 11).

Table 11: Number and proportion of episodes of general hospital care in people with learning disabilities recorded as an emergency.

Period	% emergency admissions			Number	
	England	South West	N. Somerset	Emergency	Planned
2005-06	50.74	48.55	24.69	98	299
2006-07	49.13	44.99	35.98	145	258
2007-08	48.62	42.24	39.89	146	220
2008-09	49.96	43.50	43.61	157	203

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Once admitted to hospital the level of specific support is varied. In UHBristol, the Learning Disabilities Liaison Team (LDT) with Learning Disability Liaison Nurses has strong links with the CLDT (Community Learning Disabilities Team) across Bristol. The liaison nurses help with planning and preparing for coming to hospital for investigations or treatments and they support people when they are in hospital both directly and indirectly by training staff in dealing with specific, individual needs. The nurses are then instrumental in supporting people in their move out of hospital to return home. The team also has a clinical alert system to make pre-admission links and provide the necessary support and advice. Additionally, ward staff receive learning disabilities and safeguarding awareness training. There is also active involvement in the discharge planning for patients.

Currently there are no liaison nurses based at Weston General Hospital. However, following the review in October 2011 from the NHS South West Acute Hospital team, work has continued to improve upon the services delivered to patients presenting with a learning disability.

It has been reported that there are issues with discharge from secondary care to primary care for those with a dual diagnoses of learning disabilities with mental health. This issue needs closer examination.

3.1.3 Cancer screening

Research shows that people with a diagnosis of learning disabilities in primary care continue to have a lower uptake of cancer screening and thus fewer recorded cancer screening results²⁸.

For North Somerset there is no data on the uptake of cancer screening - cervical, breast and bowel cancer - in people with learning disabilities. There is also no data on the uptake of other screening programmes, Abdominal Aortic Aneurysm (AAA) screening and diabetic retinopathy screening, or for the NHS Health Checks.

3.1.4 Learning disabilities and mental health

People with learning disabilities have significantly higher rates of mental health problems than the general population. Anxiety and depression are particularly common amongst people with Down's syndrome, and there is evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population²⁹. There is limited local current data on service use of people with learning disabilities for mental health services. The North Somerset Learning Disabilities profile indicates that recording of learning disabilities in those admitted to psychiatric in-patient

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unit is extremely low – 4.9% in North Somerset compared to 55.6% for England (2005/06 – 2008/09). For further details of rates and trends, see the adult mental health chapter of the JSNA.

Best practice will ensure that people with learning disabilities and mental health problems are enabled to access mainstream mental health services with support from specialist learning disability services as appropriate.

The recommendations coming out of the Winterbourne View review need to be implemented locally. These include:

- Health and Wellbeing Strategies should include the needs of the whole population and aim to reduce the number of people using in-patient assessment and treatment services;
- Social care partners should review strategies and policy regarding those whose behaviour challenges services, ensuring there is a clear focus on preventing escalation within community settings, good local provision and support, and clear criteria for situations in which specialist placements outside mainstream services are required;
- Generic mental health services, as part of their annual contract monitoring, should identify the steps taken to enable citizens with learning disabilities and autism to be supported in their own communities and familiar localities;
- There should be comprehensive knowledge of any services to be used, including any adverse incidents, absconding, police attendances in the interests of patient safety, criminal investigations, safeguarding investigations and occurrence of Deprivation of Liberty Safeguards applications and renewals, and outcomes;
- Standard NHS contracts should be used for all ‘spot purchased’ patient placements, including both quality and safety measures, and in particular requirements for the commissioner to be informed directly of any untoward incident;
- The performance of the provider should be assessed against the contract on a regular basis;
- Assessment and treatment inpatient services should publish information concerning (i) direct patient related costs (ii) their service costs (iii) the specific rehabilitation gains of individual patients (iv) the detention status of patients at the point of discharge, and whether or not discharge is to a within-service facility owned by the same company, an associated company or NHS Trust.

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3.1.5 Community Team for People with Learning Disabilities

The Community Team for People with Learning Disabilities (CTPLD) is a joint, multidisciplinary, co-located team offering health and social care services to people with a learning disability. It is made up of managers and specialist staff including a team specifically responsible for work with challenging behaviour. The main responsibilities of the team are:

- To support people to have equal rights and responsibilities in society
- To support people to be as independent as possible
- To help people to speak up for themselves and have more choice
- To support people's inclusion within society
- To support family carers and staff in their caring role
- To promote equal access to health care at the point of delivery and through to aftercare

A person with a learning disability is eligible for CTPLD services if they have significantly reduced ability in understanding new or more complex information or in learning new skills. This is usually where a person's IQ is below 70. They will also have a significant reduction in their ability to cope independently and have a disability that started before adulthood with a lasting effect on their development.

If a person with a learning disability does not meet the CTPLD eligibility criteria, there are services available from other social service departments, third sector services and voluntary services that can support an individual and their carers or family with their needs associated with their learning disability..

In cases where an individual with a learning disability does not meet the eligibility criteria, the CTPLD will support them and their family by offering advice and information on other appropriate services that might help them.

Following the Joint Commissioning Strategy for People with Learning Disabilities, the services that are commissioned for North Somerset are those that fulfil the following criteria. Services should

- be person centred
- promote increased choice and control for people
- encourage greater involvement in peoples own communities
- maximise a person's independence
- offer the greatest opportunity for social inclusion
- achieve best value and the best outcomes for people with learning disabilities
- promote effective partnership working across agencies, with increasing support available from mainstream services.

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The specialist services offered by the CTPLD will also include the following essential elements:

- Assessment and review
- Health promotion
- Health facilitation
- Health care management
- Personalised care planning
- Hospital admission avoidance
- Hospital discharge facilitation
- Transition planning (children to adult and other transitions throughout life)
- Housing advise
- Training
- Service development

In addition the CTPLD are also able to offer a range of services and support from staff with highly specialised skills and knowledge in areas that include:

- Advanced communication skills
- Working with people whose behaviour challenges services
- Deprivation of liberty assessment
- Supporting family carers
- Complex epilepsy
- Complex health needs
- Autistic spectrum disorders
- Specialised psychiatry
- Specialised psychology
- Assessment and management of mental disorder and illness
- Risk assessment and management
- Postural management
- Specialist Continuing Health Care assessment
- Assessment of capacity in complex situations
- Dysphasia
- Assessing whether a person has a learning disability

North Somerset has a very mature and well developed independent sector of care services including provision in nursing and residential care, housing and personal support, day occupation, employment and social training. There are many different providers, ranging from small single service providers to large national organisations. Similar diversity is reflected in the type of provider with a range of private individuals, small private companies, local charities, national charities and large independent provider organisations.

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During 2011-12 the total number of working age adults (aged between 18 and 64) with learning disabilities known to social care was 421. The previous year, this total was slightly higher at 428.

3.1.6 Transition from Children to Adult Services

For all young people, the transition from childhood to adulthood is an all-encompassing process. It involves consolidating identity, achieving independence, establishing adult relationships and finding meaningful occupation.

Supporting young people with additional complex needs – for example, young people with severe learning disabilities, a significant physical or sensory impairment or severe and enduring mental health difficulties - in their transition to adulthood can be a challenge to service providers because the process must be individual to the needs and aspirations of each young person. The challenge is compounded by the young person’s move from the care of one service to another at different ages. Commonly, these transitions can occur independently of each other which means that young people and their families may repeatedly have to deal with new agencies and professionals.

It is recognised that some young people who do not fall into this group, but who have significant levels of additional needs, will still need support from other services and will need their pathway to on-going support clearly signposted.

Over recent years there has been increasing recognition of the need to improve transition planning and support for young people with additional complex needs. There is widespread understanding of the need to co-ordinate this support across a range of agencies including health and social care, education, housing, employment, Information, Advice and Guidance providers, benefits, youth and leisure services.

For some young people with additional complex needs, having access to timely and comprehensive information may be enough to help them reach their goals. For others, more support may be needed during this transition period from a range of services to enable them to reach their potential.

Transition planning is the process of planning for a young person’s future and should include all aspects of life. This happens within schools for all young people with a Statement of Special Educational Needs and takes place between the ages of 13 and 19. It prepares the way for a successful and smooth transition; enables parents, carers and young people to understand what is available to them in the future; and ensures that services can plan for the young person’s future in a co-ordinated way.

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The number of young people with complex additional needs who went through transition during 2011-12 was 21. Of this group, 13 were male and seven female. Following transition, 19 continue to live locally in North Somerset, with one now attending a residential college and one placed out of area in Gloucestershire.

Over the next few years a steady increase in cases transferring from children to adult services is expected. In 2012-13, 39 young people are known to be reaching the age of 18 and requiring adult social care. Figures for the following years of young people who will be coming through transition are shown in Table 12.

Table 12: Number of young people expected to transfer from children to adult services

Year	Number
2012-13	39
2013-14	30
2014-15	48
2015-16	49
2016-17	59

Details of all young people who are coming through transition with complex additional needs are recorded on a newly developed database for North Somerset. A protocol outlines the process of transition, supported by information packs and leaflets, together with a continued emphasis on clear communication and supportive relationships amongst professional groups and the parents or carers.

In addition, young people finishing residential college require adult services on their return to the area. In 2012-13 there are nine such cases incurring a cost of around £230,000 per year.

3.2 Carers

In 2011, the estimated number of people with learning disabilities aged under 65 years and living with a parent was 242. The proportion of people with learning disabilities living with a parent declines with age from 62% in the age group 20 to 24 to 5% in the 60 to 64 age group.

The *Valuing People White* paper suggests that one third of all adults with a learning disability living at home do so with carers aged over 70 years of age. Evidence from elsewhere shows that many older family carers have had little contact with statutory services in the past, and many do not make plans for the future. Support for older family carers to plan for their own future will be needed to avoid the risk of family care breakdown.

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During 2011-12, 157 Carer Assessments were carried out in North Somerset, all of which were joint assessments between the carer and client.

In North Somerset the Shared Lives Scheme provides support and accommodation in a family home for people with learning disabilities. The carers support people to live an ordinary life as part of their family and their community, to meet new people and make new friends. Carers help people to become a more independent adult by developing the skills they already have and learning new skills. They also help people to make their own life choices.

Shared Lives placements are particularly successful as the individual is able to choose their own carer. The North Somerset Shared Lives Scheme recruits carers who are able to demonstrate that they are right for the role and have been trained to ensure they have the right skills and knowledge to carry out their duties. Placements are then arranged with a full specification set out in a support plan, together with a placement agreement and tenancy agreement agreed between the service user and carer. Placements are monitored and reviewed regularly. The Care Quality Commission also instigates checks to ensure that the service is of a high standard.

3.3 Support for Healthy Lives

There are a range of services aimed at improving healthy lifestyles available across North Somerset. These include services to address sexual health, obesity, dental health, healthy eating, physical activity, smoking, alcohol and drugs. However there is a need to specifically look at access issues to ensure that there is equity of access for people with learning disabilities.

A new scheme to increase the number of people with disabilities taking part in sport regularly will be delivered from January 2013, initially for three years. The 'Sportarray' project has consulted with 64 people with learning disabilities and 15 local disability organisations to steer the focus of the project which has received funding from the National Lottery following a successful bid to Sport England's Inclusive Sport Fund. It is hoped that this project will have an impact on the number of individuals with learning disabilities who are regularly involved in some form of physical activity. There is also potential to increase levels of physical activity with activities such as gardening, dancing.

3.4 Advocacy

Advocacy is a method or tool used to ensure people are able to participate fully in making decisions about issues which may affect their lives. People with a learning disability quite often lack the confidence or social skills they need to be able to express their own views, opinions and decisions. Advocacy, when used

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correctly with people according to their needs, can enable a person to participate in decisions about issues, which may affect their life. This engagement can make a very positive impact on the person's life as it helps them to say what they want, ensure they are aware of their rights and enable them to express their views so that they can access the services they need.

It is a key national priority to ensure that for access to public services the users are put first. This will be achieved through a reform of public services, enabling people to live their own lives as they wish, confident that services are of high quality, are safe and through the promotion of their own individual needs for independence, well-being and dignity. This wish to have as much choice and control as possible over their own lives through advocacy and a person-centred approach is also the wish of people with learning disabilities and their families. North Somerset shares this ambition and is committed to making this happen.

Access to support, to speak up and to voice one's views and needs is a basic right. North Somerset has a number of advocacy organisations providing these services including North Somerset People First; Your Say; Friend (IMCA); and PALS, through Weston General Hospital (although not learning disability specific).

Some individuals miss out on using advocacy services because they are not eligible to receive a service and in some instances due to the funding requirements set out in contracts, organisations are forced to turn away people who would benefit from this service. Some individuals may then experience crisis situations which are ultimately costly, stressful and could have been avoided. However time and cost implications may lead to some individuals in a position where they are unable to access further advocacy time.

3.5 Self directed support

North Somerset is increasing the number of people using an Individual Budget for self directed support. The principles of choice and control are critical to this policy development and Person Centred Planning must remain the key underpinning principle to gaining more choice and control. The primary impetus of an Individual Budget is to ensure that service users are given their fundamental right of decision making concerning their own care and in taking control in the design of their individual care package, ensuring that it meets their own specific needs.

In North Somerset, the number of adults with learning disabilities receiving personal budgets has increased from 77 in 2009-10 to 127 in 2010-11; and to a total of 210 in 2011-12. The variations in how individuals receive their budget are detailed below in Table 13.

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Table 13: Adults with learning disabilities in North Somerset receiving personal budgets in March 2012

	Age		Total
	18 to 64	65+	
Direct payment	20	0	20
Cash Personal Budget	48	0	48
Managed Personal Budget	109	20	129
Mixed Personal Budget	13	0	13
Total	190	20	210

Source: ASC-CAR returns 2011-12 to the NHS Information Centre

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3.6 Employment

For people with learning disabilities, gaining employment is an important aspect of achieving a full and rewarding life. Paid work provides recognition of a valued social role, useful day time occupation, important social opportunities and in a few cases, a helpful level of financial reward. Government policy has emphasised the importance of maximising work opportunities for people with learning disabilities since the publication of *Valuing People* in 2001.

In 2010-11, the proportion of people with learning disabilities aged 18-69 who were employed and known to North Somerset Social Services was 9.3%. This is significantly higher than the England average of 6.3% and represents an increase from 2009-10 where employment in North Somerset was 7.9% compared to 6.1% in England.

Table 14: Adults with learning disabilities in employment

	2008-09	2009-10	2010-11
North Somerset	3.4 (20)	7.9 (35)	9.3 (40)
South West	3.2	5.4	5.4
England	3.2	6.1	6.3

www.ihal.org.uk/profiles

In North Somerset, 43 people with learning disabilities were in paid employment during 2011-12. This represents 10% of the total number of adults of working age. It should also be noted that 51 (12%) people are involved in voluntary work, some of whom are also in paid employment (Table 15).

Table 15: Employment in North Somerset of working age adults with learning disabilities (age 18-64) during 2011-12

Employment	Residential care services	Community based services	No Services	Total
Paid for more than 16 hours	-	1	-	1
Paid for less than 16 hours	13	22	5	40
Paid less than weekly	-	2	-	2

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				43
Unpaid voluntary	13	34	4	51
Total working age				421

www.icapp.nhs.uk

The Carlton Centre offers a vital resource for people with mild learning disabilities by providing access to employment support. Further details are included in the mental health chapter of the JSNA.

3.7 Housing

People with learning disabilities can face many difficulties when arranging where they live. The types of accommodation available to people with learning disabilities can be divided into two groups. Settled accommodation describes living arrangements where a person can reasonably expect to stay as long as they want and unsettled accommodation is either unsatisfactory or somewhere, like in residential care homes, where residents do not have security of tenure. Settled accommodation provides a stable environment, which when linked to supportive social care, has been shown to contribute to improved outcomes for adults with learning disability.

Settled accommodation might include being an owner occupier or part of a shared ownership scheme. The individual might rent accommodation as a tenant; live with family or friends; live in supported accommodation; be part of an adult placement scheme; live in approved premises for offenders or those under probation; live in sheltered housing or in mobile traveller accommodation.

Table 16: Adults with learning disability aged 18 to 64 years living in settled accommodation

Period	North Somerset	South West	England
2008-09	17.1	30.9	33.3
2009-10	50.6	50.9	60.6
2010-11	54.6	44.5	59.0

<http://www.improvinghealthandlives.org.uk/profiles/index.php?pdf=E06000024>

In 2010-11, the proportion of people with learning disabilities living in settled accommodation in North Somerset was 54.6%, lower than the England average but higher than that for the South West (Table 15), and showing an upwards trend. The figure for 2011-12 shows a further increase to 60.3%.

Non-settled accommodation might include rough sleeping or squatting; living in a night shelter, emergency hostel or refuge; being placed in temporary

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accommodation or staying as a short term guest with family or friends; being a hospital patient; staying in a registered care home or staying in prison. In North Somerset the percentage of adults with learning disabilities living in non-settled accommodation in 2010-11 was 41.9%, significantly worse than the average for England and also higher than the South West average (Table 17. This figure has continued to rise in 2011-12, with a percentage of 50.0% now registered as living in non-settled accommodation in North Somerset.

Table 17 Adults with learning disability aged 18 to 64 years living in non-settled accommodation

Period	North Somerset	South West	England
2008-09	17.1	14.4	14.4
2009-10	49.4	24.3	21.8
2010-11	41.9	21.2	20.1

www.ihal.org.uk/profiles

Looking at local authority figures for the types of accommodation for working age adults with learning disability, it is apparent that social services departments do not know about everyone. However the percentage of adults with learning disability known to the local authority, but for whom no information about accommodation is available, is very low in North Somerset. In 2010-11, accommodation information was missing for only 3.5% of local adults with learning disability, significantly better than the average for England (21%).

Some types of accommodation, such as squatting or using night shelters, could be seen as serious emergency situations for people with learning disability. These situations are undesirable for anybody, but for people particularly likely to be vulnerable to abuse or exploitation, or in need of particular support they are especially serious. Local numbers in this situation are fortunately low.

The introduction of *Valuing People* in 2001 set new and bold challenges to local authorities and health providers alike. These challenges aim to promote independence and enhance the quality of life for people with learning disabilities.

Supported living provides a high quality of support and care, and meets some of the basic rights people with learning disabilities should be afforded. This is the right to choose where they live and with whom, and who provides support and care to them. Supported Living options provide individuals with a home for life and are not subject to variations in the market, like the rise and fall of Nursing and Residential Home provider. The accommodation in Supported Living is completely separate to that of the support and care, which means if a service user has an issue with a provider of care they can change this arrangement without putting their home at risk.

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Supported Living means people have a secure home, a right not afforded to individuals in care and/or in nursing homes. This fundamental right has been linked to the Human Right Act and as more and more young people with learning disabilities and their families raise their expectations, so a demand will come from service users for this facility.

Supporting People provides housing related support; through grants it enables and empowers service users to become as independent as they can. It aims to keep service users safe and to have a fulfilling life. Since its introduction, Supporting People has resulted in hundreds of vulnerable people being able to live in the community in ordinary flats and houses.

The Housing Strategy and Commissioning Team has been working with the CTPLD on numerous areas including the re modelling of care homes to provide more affordable housing solutions. This has included direct work with care providers including Shaw, Mencap, The Freeways Trust and Brandon Trust.

Strong relationships have also been forged with local housing associations especially Alliance Homes, who are currently identifying properties for purchase with capital monies. Private rented accommodation and extra care housing are also being researched for use by the local population.

3.8 Education

There are range of services at schools in North Somerset to support children aged 14 and above.

In addition, specialist provision is offered at Weston College. All learners with additional support needs are given access to the full curriculum and are encouraged to work towards meeting their full potential with personal support. A dedicated Learning Support Team with experience and knowledge of a range of learning disabilities works with individuals to identify and arrange the necessary support to enable students to achieve their individual learning goals.

Within learning support there are specialists in a variety of areas that include:

- Autistic Spectrum Condition
- Specific Learning Difficulties - Dyslexia/Dyspraxia
- ADHD/ADD
- Emotional and Behavioural Difficulties
- Severe and Complex Learning Difficulties
- Mental Health Issues.

Individualised support programmes are tailored to each individual and may include in-class support, specialist support, specialist teaching, small group

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workshops, equipment support, assistive technology and diagnostic assessments.

In addition, a new specialised training facility for learners on the autistic spectrum has been established at Weston College. It consists of accessible and sustainable training that includes a residential element to develop both independent living and employability skills. It has been designed to increase learner participation, achievement and success by catering for small numbers of learners (up to 15).

All learners, wherever they are on the autistic spectrum, learn to understand and manage their learning difficulty within a supportive and progressive environment. Learners are supported to go on to achieve independent living, further and higher education courses, apprenticeships, work-based training and improved career opportunities.

3.9 Safeguarding

In 2011 there were 642 people aged 18 or over known to the North Somerset Community Team for People with Learning Disabilities³⁰. Three quarters of this number (489 people) with a learning disability were receiving funding from North Somerset Council during this year and of these, 37 (7.6%) were referred under the safeguarding procedures.

Over the last three years there have been 75 referrals under the safeguarding procedures for people with the Primary Client Category of Learning Disability. The total number of referrals over this period has increased slightly and there continues to be similar number of referrals for both men and women (Table 18). The information shown relates to the total number of referrals, which may include more than one referral for an individual person. The data also includes people with a learning disability who may be funded by another Local Authority or may not be currently in receipt of services.

Table 18 Referrals under the safeguarding procedures for people with Learning Disabilities (2008-09 to 2010-11)

Year	2008-2009			2009-2010			2010-2011		
Gender	Female	Male	Total	Female	Male	Total	Female	Male	Total
Number of Referrals	35	31	66	29	20	49	40	35	75

Source: North Somerset Council

The majority of cases (68%) were referred by the CTLD and 69 (92%) of these were in the age group 18-64 (Table 19).

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Table 19 Safeguarding referrals for people with the Primary Client Category of Learning Disability (2010-11)

	Age group		Total	% of total
	18-64	65+		
CTPLD	46	5	51	68.0
Safeguarding team	18	1	19	25.3
Clevedon ACLT	2	0	2	2.7
Weston ACLT	2	0	2	2.7
Worle ACLT	1	0	1	1.3
Total	69	6	75	100

Source: North Somerset Council

The majority (73%) of the referrals for safeguarding were either substantiated or partially substantiated (43% and 31% respectively) (Table 20)

Table 20: Learning disabilities referrals for safeguarding by conclusion (2010-11)

Conclusion of referral	Total
Substantiated	32
Partly Substantiated	23
Not Substantiated	12
Not determined / Inconclusive	7
Investigation ongoing	1
Total	75

For more details and recommendations, see the Safeguarding Adults JSNA chapter.

3.10 Costs

There are a range of data sources used by the NHS and social services. This section provides an overview of two of them.

Local Authority spend

In 2011-12, North Somerset Council spent £ 18.5 million on services for adults of working age with learning disabilities and a further £1.2 million on services for older people. In addition £900,000 was spent on the Supporting People programme and £814,600 on staffing costs.

During this period, much of the council funding went on residential care; representing 55.8% of the total spend. The areas receiving funding are shown in Table 21.

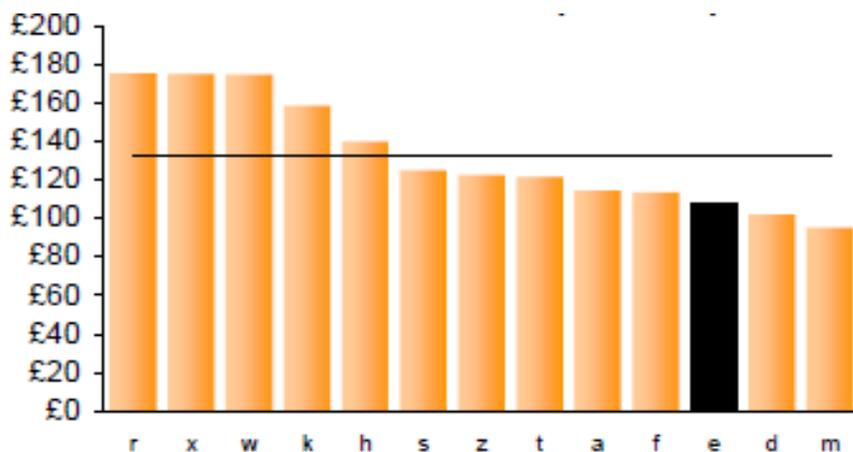
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Table 21: Expenditure by North Somerset Council on adults with learning disabilities during 2011-12

Area of expenditure	Total
Residential	10,295,999
Nursing	657,653
Purchased Home Care	286,250
Extra Care Housing	165,095
Day Care	2,262,807
Respite	258,813
Supported Living	2,984,356
Direct Payments / IB	1,535,996
TOTAL	18,446,969

These costs represent a relatively low expenditure when compared to other similar authorities. The net expenditure per head for adults with learning disabilities in North Somerset in 2010-11 was £107.2, lower than the average of £132.6 (Figure 4).

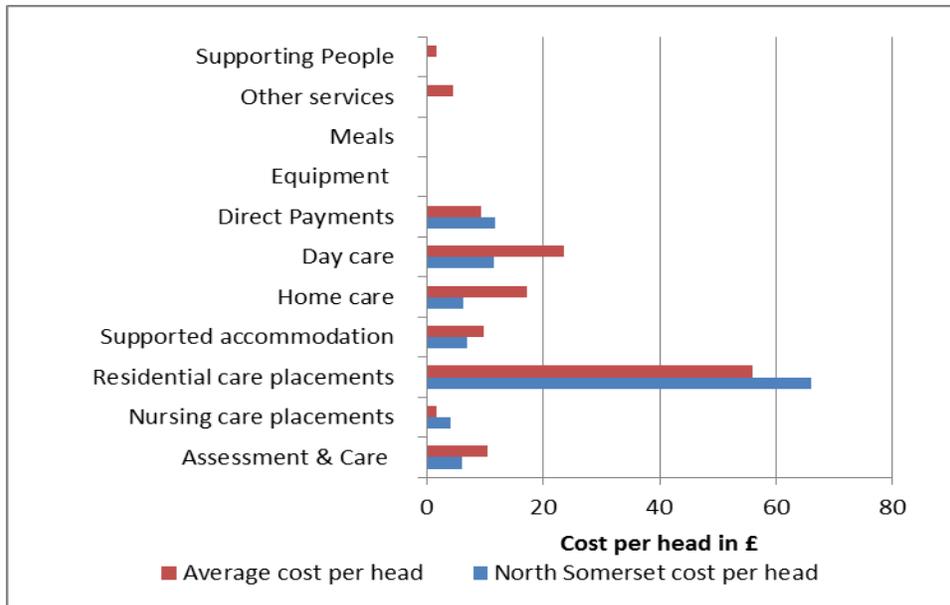
Figure 4: Total net expenditure per head for adults with learning disabilities in local authorities during 2010-11 (North Somerset marked in Black)



In most areas, the expenditure for North Somerset is lower than those for the average similar local authority area. The breakdown of costs per head is shown in Figure 5. This also highlights the apparent higher expenditure on residential care. However the real expenditure locally is hidden due to the current higher than average placement activity. It should be noted that residential care is currently provided for 186 adults with learning disability, but this includes 148 preserved rights cases. So in fact, the real number of placements is actually low and expenditure lower than average.

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Figure 5: Costs per head for adults with learning disabilities in 2010-11



NHS spend - Programme Budgeting

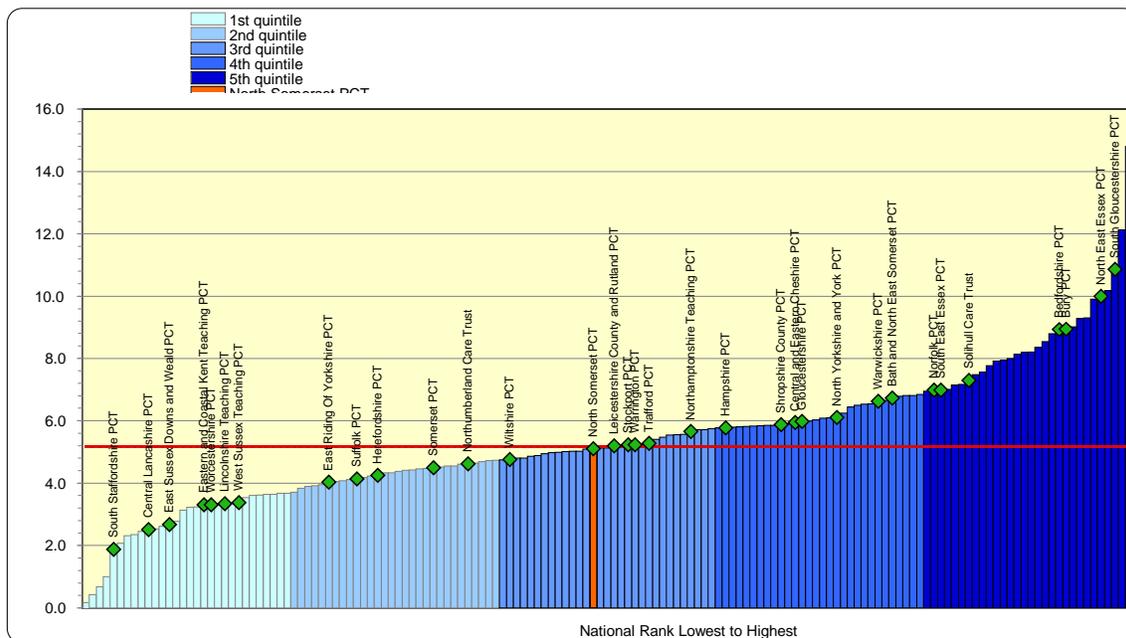
In the 2010-11 period the Primary Care Trust spent £2.1 million on learning disabilities.

Programme budgeting is a method of analysing NHS expenditure across 23 key healthcare programmes such as cancer, mental health and learning disabilities. It provides an appraisal of past resource allocation with a view to tracking future spending in those areas. It is often used in combination with marginal analysis, a method of appraising the added benefits and costs when a new investment is proposed (or the loss of benefits and lower costs from disinvestment).

In 2010-11 the programme budgeting data reported an estimated expenditure of £2.8 million on learning disabilities in North Somerset. This was slightly lower than for PCTs with similar demographic and geographical characteristics (the ONS cluster) (Figure 6).

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Figure 6: Programme Budgeting Expenditure in Learning Disabilities per 100,000 population in PCTs (2010-11)

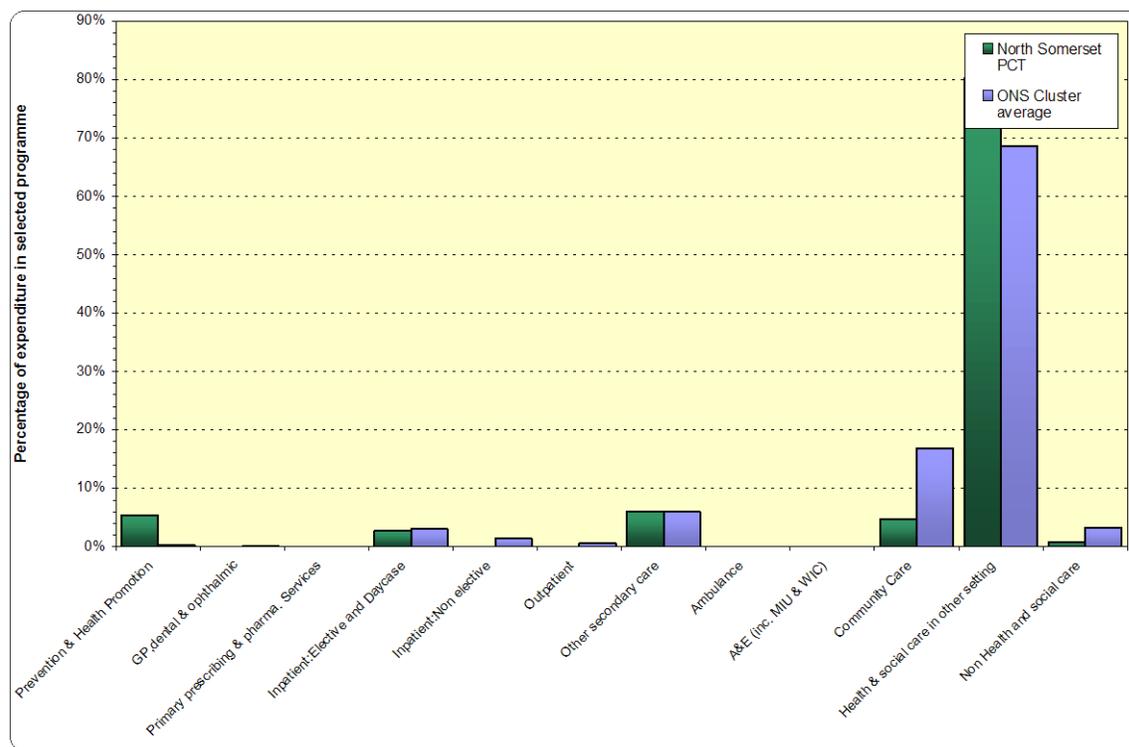


Source: Department of Health

The guidance for the programme budgeting return stipulates that all spending on learning disabilities services should be allocated to ‘health and social care in other settings’. Similar to other areas, 80% of the spending on learning disabilities was allocated in this way (Figure 7).

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Figure 7: Programme budgeting spend in North Somerset by setting for Learning Disabilities (2010-11)



Source: Department of Health

5. What do people think?

In November 2011 members of North Somerset People First, a local support organisation for people with learning disabilities carried out a mystery shopping exercise to departments of Weston General Hospital. The aim of this visit was to see how people with learning disabilities are treated by staff at the hospital. Some of the positive findings included:

- Staff at the main reception desk were helpful and gave clear directions
- The pharmacy staff took time to listen to the visitors and treated them with respect
- Many initial contacts with staff were positive and friendly
- When the lack of easy read information was pointed out to staff, the visitors were told that this omission would be addressed and new

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information produced

Less positive experiences recorded during this visit included:

- Some department staff were not particularly helpful
- Easy read information is not available consistently across departments
- Signage to wards, departments, lifts and toilets is not always clear
- Some staff spoke to the supporters rather than the visitor themselves

These findings build on those identified through a consultation exercise that was undertaken in 2007 with people with learning disabilities, their families and support staff. This included forum meetings and individual interviews, followed by a conference, Fulfilling Lives, in July 2007 where the results were fed back to approximately 250 people.

The main findings from this consultation suggested that people with learning disabilities, their families and their support staff in North Somerset wanted very similar things:

- Employment:
There was general agreement about the importance of employment. Many people want paid jobs, and all parties agreed that there should be more job support. Support staff suggested that their own roles could move towards supporting employment. The employment projects which are now coordinated across North Somerset were seen as very positive. However people expressed the need for further opportunities in such places as the Pottery, and the Barcode Café. Generally, people were very happy to receive employment advice.
- Community:
Parents stated that they wanted activities and bases to be local. People themselves wanted to get out more and 'do things that other people do'. Support staff also saw their jobs as moving into the community.
- Community Support:
In order to get community support right, it was recognised that person-centred plans (PCP) were needed. This was a particularly strong theme from parents. However people with learning disabilities and support staff also wanted services to become more 'person-centred'.
- One to One support:
One to one support workers were seen as important. Parents particularly wanted support workers that they could know and trust. People themselves

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wanted the right support, so that they could choose what they wanted to do in their lives.

- Relationships:
Friendships and relationships were seen as vital. People with learning disabilities wanted to socialise, to make new friends, to have relationships and to learn more about sex.
- Discrimination:
As people with learning disabilities become more involved in the community, the wider public will become more aware of them and of what they have to offer. However support staff were especially aware of the ignorance and discrimination that is sometimes out there. People with learning disabilities themselves called it 'bullying' and 'hate crime'. They would like social services to help them tackle this problem.
- Working together:
Progress already made, was acknowledged. People were happy with many things that had been set up in North Somerset, such as the Scotch Horn Centre. It was recognised that the new task was to build on successes whilst continuing to work together - with families, support staff and with people with learning disabilities themselves.

In June 2012, the Learning Disabilities Health Summit attended by people with learning disabilities, their carers and staff from the community learning disabilities services identified a number of priorities following a presentation about the North Somerset Joint Strategic Needs Assessment. These priorities were:

- Increasing employment opportunities;
- Psychiatric liaison nurse in Weston Hospital;
- Addressing levels of obesity and underweight;

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6. What works

Policy

The central government's three year strategy *Valuing People Now (2008)* recognises that more work is needed to implement the recommendations from the White Paper *Valuing People (2001)*, especially around personalisation, meaningful daytime activities including employment, fair access to good quality health care services as well as giving people with learning disabilities more choice about where they live.

Valuing People Now retains the principle outlined in *Valuing People* that people with learning disabilities are people first. It recommends that people with learning disabilities should participate in society as fully as possible with a voice regarding decisions about their care. It also contains key targets for those in receipt of services such as:

- 5% increase in the proportion of people with home tenancies or ownership
- 40% of individuals in paid employment by 2025

Other priorities set out in the strategy are to set up person-centred plans and personal budgets, thus increasing choice and control and improving health and wellbeing outcomes.

The national strategy highlights those people with learning disabilities that are least often heard and most often excluded. It stresses that local work needs to ensure that these groups of people are included in planning and support. These include people with more complex needs; people from black and minority ethnic groups and newly arrived communities; people with autistic spectrum conditions; and offenders in custody and in the community.

Valuing People Now built on national reports and guidance for the health and social care of people with learning disabilities. These included:

- ***Mansell Report (2007)*** *Services for people with learning disability and challenging behaviour or mental health needs*. This report set out good practice guidance for effectively meeting the needs of people with challenging behaviour. The guidance emphasised the continuing neglect of the needs of people with learning disabilities whose behaviour is seen as 'challenging', many of whom remain placed 'out of area', often in costly services that are of poor quality, for long periods of time.
- ***Healthcare for all (2008)***. This report followed an independent inquiry into access to general health services and healthcare support. It states that NHS bodies should ensure that they provide health services to adults with profound intellectual and multiple disabilities with a focus on weight

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management, dysphagia, epilepsy and resolution of pain and distress.

- **Six Lives (2009).** This report of the health services and social care ombudsmen, responded to the six cases highlighted by the charity Mencap in **Death by Indifference**. Complaints had been set out following the deaths of six people with learning disabilities who died whilst in NHS or local authority care in 2003-05. The report shows that on many occasions basic policy and guidance were not observed, the needs of people with learning disabilities were not accommodated and services were uncoordinated. It also highlighted insufficient training of staff, misconceptions and risk of institutional discrimination of adults with learning disabilities. The report demonstrated a need for training and stronger leadership throughout the health and care professions.

Following events at **Winterbourne View Hospital** in May 2011, the Department of Health wrote to PCT and Local Authority Chief Executives in order to remind commissioners of the minimum action they were expected to take to improve quality locally. Actions included continuing to support the improved uptake of health checks and completion of the annual Learning Disability Health Self-Assessment. The interim report on Winterbourne View published by the Department of Health also contains a number of actions for commissioners including the need to focus on commissioning prevention and early intervention services, and the need to develop person centred approaches across commissioning and care.

Evidence base

There is only limited research on the cost effectiveness of different models of care for people with learning disabilities, which presents challenges for making effective and appropriate policy and practice decisions. Costs related to services for people with learning disabilities can be considerable. The average annual cost of social care and housing per person with learning disabilities over 60 years old can be estimated as £41,080 with 74% of this cost spent on accommodation³¹. Cost then increases for those with more severe disabilities and with mental illness.

Housing – a study comparing costs and quality of life for adults with low support needs did not find any major difference in lifestyle outcomes between adults with learning disabilities living in fully staffed or semi-supported living accommodation. However, it was found that people living in semi-supported accommodation had better choice and involvement in community activities. In addition, the costs were lower. People in fully staffed accommodation, such as residential care homes, had better outcomes for some health indicators and for money management. Thus it was suggested that semi-supported living was more cost-effective than residential care, but attention is needed to ensure people in semi-supported living were provided with enough health and financial advice support³².

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Employment – studies included in *Valuing People Now* highlight how employment support can improve wellbeing; reduce challenging behaviour and the need for residential care, with financial savings as a result. A supported employment service in Kent has shown that for every person supported into work there is an annual saving of £1,290 to the council and of more than 33,500 to the taxpayer³³.

Health care – health check interventions were found to be more cost-effective and cheaper compared to general care in a recent study. However there were a limited number of studies on the cost effectiveness of health care³⁴.

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7. Recommendations for consideration

Based on the policy context, the local situation and the evidence base, it can be deduced that the key challenges that will ensure clear development and improved services for people with learning disabilities will include the following:

1. **Improve recording** of learning disabilities within North Somerset, with the development of a joint NHS and Local Authority learning disabilities register and improved recording in mainstream services.
2. **Ensure access to mainstream services is equitable**, including uptake of screening, lifestyle services, learning disabilities liaison nurses, and dentists.
3. **Review diagnosis and access to mental health** services for people with learning disabilities, including use of diagnostic tools in primary care.
4. **Ensure effective transition** arrangements are in place for children and young people – this needs to be informed by consultation with service users.
5. **Quality assurance** of local specialist health and social care providers that work with complex learning disabilities needs to be improved. An audit of health checks in primary care should be undertaken.
6. **Levels of employment** for people with learning disabilities need to increase within both the statutory and private sector. Schools and local employers should to be proactive in finding opportunities.
7. **Repatriate or resettle** all those people who have been placed at a great distance from their ordinary place of residence.
8. There needs to be an emphasis on **moving people out of residential care** and into supported living.
9. There is a need to ensure people with learning disabilities have flexible and individualised packages of support including use of **personal budgets**.
10. **Address bullying, harassment and safeguarding** through training of frontline staff, support, and systematic monitoring.

Also see chapter on carers for further recommendations to improve respite and access to education and employment opportunities.

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Version Control

Date	Author	Version	Amended Sections	Summary of Change	Changes to recommendations
Feb 2013		V 1.0			

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